Ontario Alzheimer Strategy ... *T r a n s i t i o n*

Roundtable on Future Planning
For People Affected by
Alzheimer Disease and Related Dementias

TOOLKIT

To accompany the ADRD Planning Framework

A Self-Assessment Tool

**for individuals and organizations
to evaluate and improve their responsiveness to
the needs of persons with ADRD and their families**

1st edition
June 2007

Feedback welcome
This toolkit is a living document and we welcome any comments you have,
both what works well and what could be improved.
Please send your feedback to the Knowledge Broker at the
Alzheimer Knowledge Exchange
knowledgebroker@alzheimeront.org

TABLE OF CONTENTS

GLOSSARY

ADRD	Alzheimer's disease and related dementias.
Alzheimer Knowledge Exchange (AKE)	An online resource connecting people, resources and ideas. It is both a repository of knowledge about ADRD and an interactive collaboration tool that facilitates the exchange of ideas, solutions, innovations and best practices among those involved in dementia care.
ASO	Alzheimer Society of Ontario.
Best practices	A methodology that has been shown to reliably lead to desired results more effectively than other methodologies.
Caregivers	May include both partners in care and professional service providers (see definitions below).
Care team	All those who participate in care and support including: people with ADRD, their family and other partners in care, medical and professional staff at all levels in health and social service organizations, and volunteers.
CCAC	Community Care Access Centres – non-profit organizations, accountable to the Ministry of Health and Long-Term Care, with responsibilities for determining visiting professional and homemaker services, admission to long-term care facilities, case management, and information and referral.
Community	The context in which a person lives, whether at home or in congregate living accommodation such as long-term care homes and retirement residences.
Decisional capacity	See "Legal capacity".
Dementia Networks	Dementia Networks serve as a vehicle to facilitate people and resources coming together to improve the system of care for people with ADRD and their partners in care. Members include local champions, leaders, key service organizations and stakeholders.
Evidence-based practice	Applies evidence from rigorously-conducted research with clinical knowledge to provide effective interventions.
Facilitated-care	Patient-driven and managed care plans that recognize people with ADRD and their families as pivotal stakeholders in decision-making for treatment, care and support of the illness.
Family Health Team (FHT)	A Family Health Team (FHT) brings together different health care providers to provide coordinated primary care. There are 150 FHTs in Ontario.

First Link	A collaborative program of the Alzheimer Society of Ottawa and Champlain Dementia Network (subsequently expanded to nine demonstration sites), the First Link program offers people newly diagnosed with ADRD and their families with links to education, peer support, information and referral to local community support agencies.
Legal capacity	The *Substitute Decisions Act* (s. 45) and *Health Care Consent Act* (s. 4(1)) define capacity as the ability to understand information that is relevant to making the decision and to appreciate the reasonably foreseeable consequences of a decision or lack of decision.
Knowledge/evidence to practice cycle	Includes the generation, awareness, access, dissemination, exchange, use and accumulation of new knowledge.
LHINs	Local Health Integration Networks – not-for-profit organizations responsible for planning, integrating and funding local health services in 14 regions of Ontario.
MMSE	Mini-Mental State Exam - a standardized test that screens for cognitive impairment.
Non-traditional service sectors	Includes, but is not limited to, financial institutions, legal services, housing, police, public transit, recreation and leisure services, and retail services.
Partners in care	The spouse, partner, family members, friends and/or volunteers who play a primary role in the care of a person with ADRD; sometimes referred to as the "informal" system of care in contrast to service providers.
Performance measure or indicator	Defines and measures progress towards a goal. For a goal of informed decision-making, for example, the percentage of people with ADRD and their families who say they have received the information they need to make a decision about their care.
Public Education Coordinators (PECs)	Initiate, maintain and deliver public education activities in the community to raise awareness of ADRD and provide support to people with ADRD and their families; may work with PRCs to deliver training and education in LTC homes.
Psychogeriatric Resource Consultants (PRCs)	Provide consultation, education and program development for staff in long term care homes, Community Care Access Centres and community support services about the complex mental health needs of people with ADRD.
Rights	Used in a general context and not the more restrictive legal definition.
Service providers	Health and social service organizations that provide professional care and services to people with ADRD; the formal system of care.

INTRODUCTION

Developing the Toolkit

This toolkit has been produced by Ontario's Roundtable on Future Planning for People Affected by Alzheimer Disease and Related Dementias (Appendix A). To fulfill its mandate, between 2004-2006 the Roundtable developed a Planning Framework to address the future impact of Alzheimer's disease and related dementias (ADRD) on government programs, communities, families and individuals.

The framework is described at a conceptual level and incorporates a vision, a set of six guiding principles, three planning pillars, and five enabling mechanisms. A diagram of these components of the framework is appended (Appendix B), and a full copy of the framework is available on the Alzheimer Knowledge Exchange website[1]. This accompanying toolkit translates the framework into more concrete terms by identifying specific actions that can be taken to put components of the framework into practice.

The toolkit was initially developed by a working group from the Roundtable (as identified in Appendix A) and then tested at several venues. This edition incorporates feedback from pilots held with the Waterloo Region Dementia Network, Champlain Dementia Network and Yee Hong Centre for Geriatric Care, and from a subsequent workshop co-sponsored by the Central East LHIN, Durham Dementia Network and Haliburton Kawartha Pine Ridge Dementia Network.

Purpose of the Toolkit

The overall aim of the toolkit is to help individuals, service organizations, researchers and governments enhance their effectiveness in supporting people with ADRD and their families. It is intended to promote cross-sector linkages across the continuum of care at all stages of the disease.

The toolkit can be approached in its entirety or one section at a time.

It can also be used at several levels to help both individuals and organizations reflect on, and set goals for, their personal and organizational practices. For example, it can be used by:

- individuals;

- staff within a team or an organization;

- management;

- organizations with their partners; and

- regional networks

When it is used as part of the planning process, the toolkit offers opportunities for ongoing enhancement of dementia care and support by guiding the implementation of recommended practices. Furthermore, any debate the toolkit generates around the table among the different people involved in dementia care and support is an important part of

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[1] Alzheimer Knowledge Exchange website: www.akeontario.org

the process (e.g., by enhancing understanding of the range of resources available, strengthening linkages, and providing opportunities for a greater understanding of all perspectives).

Using the toolkit may help you to:

- develop a regional plan/strategic plan and network for dementia care;

- reflect on how to incorporate best practices in dementia care;

- monitor year-to-year improvements;

- stimulate multidisciplinary, cross-sector discussion;

- expand your knowledge of the resources available in the community;

- demonstrate, as a point of pride, the standard of care provided; and

- develop processes to support accreditation (where appropriate).

Format of the Toolkit

There are three sections to the toolkit:

1. A brief description of the guiding principles of the framework that should underlie all planning for those affected by ADRD.

2. A checklist comprising a series of reflective questions and goals that identify specific actions to guide the adoption of various components of the framework. The questions are consistent with the guiding principles and address each of the three planning pillars, which promote:
   - An Informed Society;
   - Enabling and Supportive Environments; and
   - Personal, Social and System Connectedness.

3. A list of resources.

While the toolkit is designed as a checklist, it is intended to act as an opportunity for reflection, to consider not only **whether** the action is undertaken, but **how** it is undertaken and **what** can be done to improve.

Guidelines for Using the Toolkit

- **Dual roles**: Where people have more than one role (e.g., as a Psychogeriatric Resource Consultant and as chair of a Dementia Network), we suggest that you use the toolkit for one role at a time. Similarly, decide if you are answering as an individual or as an organization.

- **Caregivers/Partners in Care**. If you are working through the toolkit as a group, consider including people with ADRD and their partners in care in the process.

- **The questions** themselves may have several parts:
   - First is a simple question asking, "*Do you* carry out a certain action?"
   - This may be followed by a reflective question asking, "*How* do you carry out that action?" The reflective question provides the opportunity to think more deeply about how well your organization or job follows the principles and

values of the framework, and to challenge existing practices. You are encouraged to develop other reflective questions specific to your setting and situations, which might facilitate thinking more deeply about what you and your organization are currently doing well and identifying areas that could be enhanced.

- In instances where it is not in your mandate to provide the specified service or your resources do not permit it (e.g., small or rural organizations), you are asked to consider the role you can play to support or redirect access to this service when it is provided by others.

- Some questions directly ask you to consider the challenges involved and the actions and resources needed to overcome them. You are encouraged to use this approach on other questions as appropriate for your organization.

- To gain maximum benefit, please answer the questions honestly. The toolkit is intended to enhance the level of dementia care and support by enabling you to identify and build on your strengths and draw attention to the areas where you could do more. It is a reflective exercise to increase awareness and education, not one of criticism.

- **Check boxes**. The simple questions include four check boxes: "Yes", "Somewhat", "No" and "Needs work". Checking the "Needs work" box acts as a flag that will indicate that future actions may be required.

- **No/not applicable**. If it appears that a question does not apply to you, we encourage you to pause and consider "out-of-the-box" solutions before deciding that you cannot do it or it is not applicable.

- **Resources**. We have suggested some resources that may be helpful in determining what more you could do to improve dementia care.

- **Goals**. At the end of each section are tables that you can use to describe your future goals to enhance services to people with ADRD and their families in the coming year and over the next five years (the "Needs work" checkboxes may provide useful input into these goals). Use as many tables as appropriate. Each table includes sections covering:
  - the goal/objective;
  - action strategies;
  - resources needed; and
  - success criteria.

THE GUIDING PRINCIPLES

A set of six guiding principles incorporates the values that underlie the framework. These principles should guide all planning and decision-making and, therefore, be reflected in goals and actions. A brief description of each of the principles is given below (please refer to the framework for more detail).

Relationship-Based Approach

A relationship-based approach to care recognizes the connections between all those involved in dementia care. While the well-being of the person living with ADRD is paramount, a person-centred approach does not recognize that the illness also affects families and that care is based on interdependencies. A relationship-based approach acknowledges that care is affected by the dynamics and interactions of at least three parties: the person with ADRD, the informal helping systems (e.g., the family and other partners in care), and the formal helping systems (e.g., health care professionals, paid care providers). This approach encourages the development of meaningful relationships and, by recognizing the diverse knowledge bases of all involved in dementia care, incorporates the broadest range of information and expertise available.

Ethical Principle of "Do No Harm"

With the increasing number of Ontarians with ADRD, special attention should be given to the various ways in which they might be harmed. Neglect, undue restraint, prescribed drug abuse, and paternalism (over-protectiveness) are some of the ways in which people with ADRD might be harmed and suffer unnecessarily. Society should be informed about the potential for harm and should recognize the total vulnerability of people with ADRD. The ethical principle of "do no harm" should be encoded at all levels in society to provide an environment in which people with ADRD can live safe and dignified lives.

Citizenry Rights

The framework is guided by the recognition of a number of citizenry rights, including:

- Autonomy and self-determination – The individual has the right to live as he or she chooses, to make decisions about his or her care to the extent possible, to have his or her preferences respected, and to remain as independent as possible.

- Interdependence – Consistent with a relationship-based approach, interdependence focuses on individuals, as members of the community, being dependent on each other and on committed relationships of mutual support. Recognizing the connections between personal, social and service-provider systems is a principle that must guide all planning.

- Full engagement in life – At all stages of the illness, the individual has the right to be fully engaged in life. This recognition of the continued potential of people with ADRD involves understanding their hopes, goals and aspirations, and assisting them to achieve them and to continue to grow and develop. It requires knowing what resources are available and providing access to meaningful interactions and activities.

- Respect and dignity - All approaches to care and caring relationships must acknowledge that all individuals, including those living with ADRD, are inherently valuable members of society. All people, therefore, deserve to be treated with respect and esteem. The maintenance of human dignity requires the elimination

of humiliating language and practices, and the stigma associated with dementia, that cause unnecessary suffering to people with ADRD and their families.

Respect for Diversity and Inclusiveness

Diversity exists at many levels and settings, and each dimension needs to be recognized with sensitivity in policy and planning decisions to avoid sweeping measures that can lead to inadvertent marginalization. An inclusive approach to care and support embraces, and responds to, the diverse needs of all members of society. Individual attributes should not create barriers to care.

Different types of diversity include ethno-cultural diversity in cities, First Nation and francophone populations, urban-rural disparities, gender differences, same-sex partnerships and marriages with attendant rights of couples, and the recognition that the needs of those with early onset dementia and those at high risk (such as people with Down's Syndrome) and their families may be different from older people with ADRD.

Fairness in Eligibility and Accessibility

Eligibility and accessibility to supports and resources should be guided by fairness. Diversity should not negatively affect a person's eligibility for and accessibility to services and support. Ensuring everyone with ADRD lives in an environment that provides the supports they need means providing programs and services that are flexible enough to respond to the changing needs of people with ADRD and their families, and that are equally accessible and available across the province.

Accountability

The overall goal of planning for ADRD is to optimize the quality of life for people living with ADRD and their partners in care. This requires accountability at all levels — by the people of Ontario to this vision, by the government to provide adequate resources and support, by health care and social service providers and the broader community to use their skills and resources to the greatest benefit, and by the individuals and their families.

At a more detailed level, this accountability includes:

  · demonstrating adherence to the principles in the framework;

  · having clear relationships between the different providers along the continuum of care and a clear understanding of the responsibilities each carries;

  · developing strong partnerships between all partners in care by identifying how all groups can work more effectively together;

  · aligning resources and capacity with the responsibility;

  · defining performance expectations and monitoring for results; and

  · taking particular care with initiatives across different sectors where traditional accountability lines may be diffused.

CHECKLIST

The checklist has three sections, organized according to the three planning pillars:

- Creating An Informed Society
- Creating Enabling and Supporting Environments
- Creating Personal, Social and System Connectedness.

For each pillar there is:

- a brief description of the planning pillar;
- a reminder to decide whether you are approaching the questions as an individual or on behalf of an organization;
- the checklist questions; and
- an opportunity to specify future goals and actions over
  - the next year; and
  - the next five years.

You can choose to work through the toolkit in its entirety or, if it is more convenient, to approach it one section at a time (e.g., completing one section every three months).

SECTION 1:

CREATING AN INFORMED SOCIETY

SECTION 1: CREATING AN INFORMED SOCIETY

Description

An informed society is an important step in eliminating the stigma associated with dementia and in assuring quality of care. The individual citizen should be knowledgeable about his or her own health as well as about situations that affect others in the community. It requires ready access to the resources that support such a degree of awareness. An informed society in the context of dementia would be one in which all members of society have an informed and realistic understanding of ADRD, one based on the experiences of those living with dementia. When ADRD-related information is effectively distributed at the individual, school, service, and broader community levels, then the preconditions for an informed society about ADRD are assured.

An informed society incorporates:

- individual and public awareness, including educational opportunities for persons with ADRD and their families;

- learning opportunities in the broader community;

- training for health and social service providers; and

- discovery and translation of knowledge and the use of best practices.

BEFORE READING ON

What "hat" are you wearing?

Before working through the checklist, decide whether you are approaching the exercise as a private individual, in your professional capacity (e.g., Public Education Coordinator), or on behalf of an organization (e.g., for a long-term care home).

A clear understanding of which "hat" you are wearing will help remove any potential ambiguity in the responses and clarify the actions forward.

Checklist Questions

Creating an Informed Society	Yes	Some what	No	Needs work
Public awareness				
1a Are you able to contribute to awareness of dementia and dementia care in the community by incorporating it into your:				
• Strategic plan/service plan (e.g., media plan, public information materials)?	☐	☐	☐	☐
• Advocacy activities with governments?	☐	☐	☐	☐
• Job descriptions/service descriptions?	☐	☐	☐	☐
• Everyday activities?	☐	☐	☐	☐
1b If yes, what do you do?				
1c If you do not have the resources yourself or it is not in your mandate, what else can you do to enhance public awareness of dementia and dementia care in your area (e.g., who can you partner with or make referrals to)?				
Information and education for people with ADRD				
2a Is <u>everyone</u> who is involved in the care of people with ADRD (including, but not limited to, those listed below) aware of the resources and services available in the community?				
• People with ADRD?	☐	☐	☐	☐
• Families and other partners in care?	☐	☐	☐	☐
• Staff at all levels?	☐	☐	☐	☐
• Volunteers?	☐	☐	☐	☐
Others in contact with people with ADRD (e.g., lawyers)?	☐	☐	☐	☐

Creating an Informed Society		Yes	Some what	No	Needs work
2b	How can you enable people with ADRD and their families to have access to the information they need to make informed choices through the progress of the disease?				
2c	How can you enable people with ADRD and their families to navigate the system, with seamless linkages throughout the continuum of care?				
	Education of broader community				
3a	Do you provide information, education and/or consultation to your community (including to non-traditional service sectors such as financial institutions, legal services, housing, police, public transit and retail services) on:				
	• How to reduce stigma?	☐	☐	☐	☐
	• Practices and interventions that reduce the risk of developing ADRD?	☐	☐	☐	☐
	• How to recognize the signs and symptoms of ADRD?	☐	☐	☐	☐
	• The ADRD services and resources available in the community?	☐	☐	☐	☐
	• How to support people with ADRD and their families?	☐	☐	☐	☐
3b	If yes, what strategies do you use, and to whom are they targeted?				

Creating an Informed Society	Yes	Some what	No	Needs work
3c	If no, can you play a role in ensuring that information, education and/or consultation is available to the broader community?				
3d	What are the challenges in providing this information, education and/or consultation to your broader community, and how can they be overcome (e.g., what resources are required)?				

<u>Basic knowledge and training for all in dementia care</u>

		Yes	Some what	No	Needs work
4a	Do you enable all members of the care team (i.e., people with ADRD, family and other partners in care, staff at all levels, and volunteers) to have basic knowledge and training in dementia care?				
	• People living with ADRD?	☐	☐	☐	☐
	• Family members and other partners in care?	☐	☐	☐	☐
	• Staff at all levels?	☐	☐	☐	☐
	• Volunteers?	☐	☐	☐	☐
4b	Do you make knowledge of, and training in, dementia care a requirement in your recruitment process?	☐	☐	☐	☐
4c	What are the challenges in enabling all members of the care team to have basic training in dementia care, and how can they be overcome? (For example, if you do not have the resources yourself, who can you partner with?)				

Creating an Informed Society	Yes	Some what	No	Needs work

Professional development/up-to-date training

5a	Do <u>all</u> health professionals, staff and volunteers in your organization have opportunities for, and access to, routine professional development to ensure that their dementia-specific knowledge and skills are current?	☐	☐	☐	☐
5b	If yes, what strategies do you use to enable routine access to professional development options for all health professionals, staff and volunteers?				
5c	If no, what can you do to enable professional development options for all health professionals, staff and volunteers?				
5d	Does your organization have individual learning plans to support and legitimize the application of learning and development into day-to-day practice?	☐	☐	☐	☐

Information sharing

6a	Do you provide opportunities for sharing information and building knowledge about dementia and dementia care:				
	• With people with ADRD and their families?	☐	☐	☐	☐
	• Among the diverse members of the care teams within your organization?	☐	☐	☐	☐
	• With physicians, Family Health Teams and other health care professionals (e.g., nurses working in acute care, physiotherapists, optometrists) in your community?	☐	☐	☐	☐
	• With partners in other organizations or sectors in your community?	☐	☐	☐	☐

Creating an Informed Society	*Yes*	*Some what*	*No*	*Needs work*
6b If yes, what are those opportunities (e.g., specialized or inter-disciplinary education and training, mentoring programs, lunch-and-learn series, training aids, First Link, on-site case-based consultations)?				
6c If no, what role can you play with others to make this information available? (For example, do you know who in your area is the liaison with the family physician, who provides information on the care path?)				
Knowledge/evidence to practice cycle				
7a Does your organization scan for and implement leading practices, and/or collaborate with and provide feedback to researchers, i.e., contribute to the knowledge/evidence to practice cycle? (For example do you connect with or seek information from university researchers, the Alzheimer Knowledge Exchange, Seniors Health Research Transfer Network, Murray Alzheimer Research and Education Program, etc. ?)	☐	☐	☐	☐
7b If yes, how do you facilitate this knowledge transfer?				
7c If no, what strategies can you use to increase the level of knowledge transfer?				

Creating an Informed Society	*Yes*	*Some what*	*No*	*Needs work*

Diversity - information

8a	Are you able to provide information to people with ADRD, their families and community, regardless of their language, religion, ethnicity, culture, sexuality, rural/urban residence, etc.?	☐	☐	☐	☐
8b	If yes, how do you address those diverse needs?				
8c	If no, what partnerships or resources do you need to facilitate this?				

Accountability

9a	Does your organization set goals with respect to its information, education, training and public awareness activities?	☐	☐	☐	☐
9b	How do you measure progress towards meeting those goals?				
9c	How else is accountability demonstrated with respect to your information, education, training and public awareness activities (e.g., by publicly reporting on these activities, through formal and informal feedback mechanisms)?				

Our Goals for Contributing to an Informed Society
(Tip: Review the boxes checked as "Needs work")

For the Next Year

GOAL/OBJECTIVE:
(Is this a personal or an organizational goal?)

Action strategies:

Resources needed:

How we will know we've achieved the goal:
(Can this performance measure be linked to your accreditation or other processes?)

GOAL/OBJECTIVE:
(Is this a personal or an organizational goal?)

Action strategies:

Resources needed:

How we will know we've achieved the goal:
(Can this performance measure be linked to your accreditation or other processes?)

Over the Next Five Years

GOAL/OBJECTIVE:
(Is this a personal or an organizational goal?)

Action strategies:

Resources needed:

How we will know we've achieved the goal:
(Can this performance measure be linked to your accreditation or other processes?)

GOAL/OBJECTIVE:
(Is this a personal or an organizational goal?)

Action strategies:

Resources needed:

How we will know we've achieved the goal:
(Can this performance measure be linked to your accreditation or other processes?)

SECTION 2:

CREATING ENABLING AND SUPPORTIVE ENVIRONMENTS

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Description

People with ADRD and their families are too often and too easily marginalized as they gradually lose friends, see important informal support systems shrink, and withdraw from participation in the wider community. Obstacles to community participation are preventable. Minimizing stigma and isolation of people with ADRD is of paramount importance.

Enabling and supportive environments incorporate:

- a functional physical environment;
- a supportive social environment;
- safety and security;
- flexible, fluid need-based access to services and support across the continuum of care;
- options in self- and facilitated-care, including job protection, income security and support for partners in care; and
- equitable approaches to rural/urban and other forms of diversity.

BEFORE READING ON

What "hat" are you wearing?

Before working through the checklist, decide whether you are approaching the exercise as a private individual, in your professional capacity (e.g., Public Education Coordinator), or on behalf of an organization (e.g., for a long-term care home).

A clear understanding of which "hat" you are wearing will help remove any potential ambiguity in the responses and clarify the actions forward.

Checklist Questions

Creating Enabling and Supportive Environments	Yes	Some what	No	Needs work
<u>Physical environment</u>				
1a Do you partner with others, including those with ADRD and their families and non-traditional sectors such as housing or transportation, to maximize physically supportive surroundings for people with ADRD:				
• In the physical accommodation and layout of their homes (e.g., bathroom fixtures, chair style, placement of rugs)?	☐	☐	☐	☐
• In the physical accommodation and layout of group residences and community service centres (e.g., long-term care homes, adult day programs, retirement residences, supportive housing, emergency rooms, dentists' offices, libraries)?	☐	☐	☐	☐
• In providing a dementia-friendly sensory environment (e.g., paint colours, noise levels, stimulation levels)?	☐	☐	☐	☐
• In the ability of people with ADRD to remain involved in their communities (e.g., signage, access to buildings, dementia-friendly transportation, family public washrooms)?	☐	☐	☐	☐
1b How could you do more?				

Creating Enabling and Supportive Environments		*Yes*	*Some what*	*No*	*Needs work*
	Supportive social environment				
2a	Do you enable relationship-centred care that provides a sense of security, sense of continuity, sense of belonging, sense of purpose, sense of fulfillment, and sense of significance[2] to be experienced by all those in the care team?				
	• People with ADRD?	☐	☐	☐	☐
	• Families and other partners in care?	☐	☐	☐	☐
	• Staff at all levels in your organization?	☐	☐	☐	☐
	• Volunteers?	☐	☐	☐	☐
2b	How do you enable these six senses for all those involved on the care team?				
	Autonomy and self-determination				
3a	Do all members of the care team recognize that a person with ADRD has the right to sustained autonomy and self-determination (e.g., respecting the person's right to live where he or she wants to live with/at some risk to self)?	☐	☐	☐	☐

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[2] As described by Nolan in, for example, Nolan, M.R. et al (2004), Beyond 'person-centred' care: a new vision for gerontological nursing." *International Journal of Older People Nursing in association with Journal of Clinical Nursing, 13* (3a): 45-53.

Creating Enabling and Supportive Environments	Yes	Some what	No	Needs work
3b Do you and the people in your organization understand what "legal capacity" (also known as "decisional capacity") means as defined in the *Substitute Decisions Act* and *Health Care Consent Act*? For example:	☐	☐	☐	☐

- it does NOT mean that a person diagnosed with ADRD is incapable of making decisions for some or all purposes;
- a person may be capable for some purposes and incapable for others and remains the decision-maker for those decisions for which he or she has the "ability to understand and appreciate" information relevant to making the decision (i.e. the capacity to make decisions may vary); and
- the MMSE is NOT a test of decisional capacity?

3c How can you ensure sustained autonomy and self-determination for people with ADRD?

Preferences in decision-making

	Yes	Some what	No	Needs work
4a Do all staff and volunteers in your organization recognize and respect the preferences and choices of people with ADRD (e.g., by having a systematic strategy or process for including people with ADRD in decision-making around care)?	☐	☐	☐	☐

4b Are you and the people in your organization aware that:

- the person with ADRD can make his or her own choices for those decisions for which he or she is still mentally capable to make (as noted above), and that, when capable, he or she **must** be included in all decisions, however small;	☐	☐	☐	☐
- if the person with ADRD lacks decisional capacity, his or her preferences and choices expressed when incapable must still, by law, be taken into consideration by that person's Substitute Decision-Maker; and	☐	☐	☐	☐

Creating Enabling and Supportive Environments				
	Yes	*Some what*	*No*	*Needs work*
• you and your staff have the legal obligation to inform the Substitute Decision-Maker that he or she must make decisions for the person with ADRD who is now incapable, first by following the wishes that person expressed when capable, and second, by making decisions in that person's "best interests" if no wishes applicable to the decision to be made are known.	☐	☐	☐	☐
4c How can you respect the choices and preferences of people with ADRD?				

Respect and dignity				
5a Does your organization have policies in place to ensure that people with dementia and their families are shown respect and dignity (e.g., policies with respect to preventing abuse and unnecessary suffering, neglect, undue restraint or over-protectiveness/paternalism, and exploring non-pharmacological options to manage behaviour prior to using medication)?	☐	☐	☐	☐
5b Do you or your organization have opportunities to regularly and critically reflect on your actions and approaches with persons with dementia?	☐	☐	☐	☐
5c How do you encourage members of the care team and the broader community (such as those in customer service) to show respect and dignity to people with ADRD? How do you go about eliminating the problem if abuse, neglect, harmful or humiliating practices are observed?				

Creating Enabling and Supportive Environments				
	Yes	*Some what*	*No*	*Needs work*
5d What actions can you personally take to enhance the respect and dignity shown to people with ADRD and their families (e.g., consider how would you want to be treated if you were diagnosed with dementia)?				
Safety and security				
6a Does your organization ensure the safety and security of people with ADRD and everyone who interacts with them, including, staff, volunteers, co-residents and program participants, by:				
• Having guidelines/policies in place for the prevention of abuse and exploitation?	☐	☐	☐	☐
• Providing a safe environment for all?	☐	☐	☐	☐
• Developing and adhering to standards of care?	☐	☐	☐	☐
• Providing sensitivity training?	☐	☐	☐	☐
• Developing a plan for addressing threats to safety and security?	☐	☐	☐	☐
6b How can you improve safety and security (e.g., by reporting and following-up on all incidents, including good catches and near misses)?				
Supports in preferred setting				
7a Does your organization, alone or in partnership with others (such as family physicians, CCACs, Dementia Networks, Psychogeriatric Resource Consultants, ASO chapters or psychogeriatric outreach services) work to ensure the following are available:				

Creating Enabling and Supportive Environments		*Yes*	*Some what*	*No*	*Needs work*
	• Needed services and supports within the preferred supportive environment (e.g., private home, retirement residence, long-term care home, supportive housing)?	☐	☐	☐	☐
	• Flexible options that enable people with ADRD and their families to live in normalized ways in their preferred setting (e.g., the option to have respite care when needed rather than at set hours)?	☐	☐	☐	☐
7b	What do you do?				
7c	If you have identified a service gap, how do you go about bridging that gap so that the needs are met and preferences respected (e.g., who can you connect or partner with, what proactive solutions do you consider)?				
7d	How could you do more?				

Creating Enabling and Supportive Environments	*Yes*	*Some what*	*No*	*Needs work*
Community service planning				
8a Do you participate in community planning activities (e.g., with the LHINs, organizations supporting multiple conditions, transportation agencies) to ensure a full range of services and supports are available for people with ADRD and their families in your community?	☐	☐	☐	☐
8b What do you do?				
8c How could you do more? Who else could you collaborate with?				
Responsive programs and services				
9a Are your programs and services responsive to the:				
• Individual needs of all people with ADRD and their families in your community?	☐	☐	☐	☐
• Continued abilities and aspirations of the person with ADRD?	☐	☐	☐	☐
• Life goals and development needs of the person with ADRD?	☐	☐	☐	☐
9b How do you assess those needs and ensure your services/programs are meeting them (e.g., direct involvement in planning and evaluation by people with ADRD and their family partners in care, formal feedback surveys)?				

Creating Enabling and Supportive Environments	Yes	Some what	No	Needs work
9c What more could be done to increase your responsiveness to meeting those needs?				
Diversity – access to services **10a** Are your services and programs accessible to all people with ADRD in your community, regardless of ethnicity, religion, culture, gender, sexuality, where they live, financial situation, etc.?	☐	☐	☐	☐
10b How does your organization recognize issues around diversity in your planning and policy decisions?				
10c How do you overcome any challenges that you face in providing fully accessible services and programs?				
10d How could you do more?				
Options for care **11a** Do you advocate, either directly (alone or with others) or indirectly (by assisting self-advocacy), for a range of options from self- to facilitated-care to be available in your community, including the provision of adequate compensation for family partners in care?	☐	☐	☐	☐

Creating Enabling and Supportive Environments	*Yes*	*Some what*	*No*	*Needs work*
11b If yes, how do you do this?				
11c If no, how could you contribute to advocating for options in care (e.g., who could you partner with)?				
<u>Workplace supports</u> **12a** Does your organization have mechanisms in place to ensure that staff and volunteers at all levels:				
• Get the support they need to provide services (e.g. how to manage workplace stress)?	☐	☐	☐	☐
• Receive bereavement support if required?	☐	☐	☐	☐
12b If yes, what are those mechanisms?				
12c If no, how can these supports be put in place?				

Creating Enabling and Supportive Environments		*Yes*	*Some what*	*No*	*Needs work*
	Workplace supports for employees who are caregivers				
13a	Does your organization have mechanisms in place to ensure that staff who are also caregivers:				
	• Have the supports they need (e.g., Employee Assistance Programs, compassionate leave of absence, flexible working arrangements)?	☐	☐	☐	☐
	• Receive bereavement support?	☐	☐	☐	☐
13b	If yes, what are those mechanisms?				
13c	If no, how can these supports be put in place?				
14a	**Workplace supports for employees with early stage dementia**				
	Does your organization have mechanisms and flexible options to:				
	• Support persons with early stage dementia to continue in their work positions as long as possible?	☐	☐	☐	☐
	• Receive support in dealing with grief and loss?	☐	☐	☐	☐
14b	If yes, what are those mechanisms and options?				

Creating Enabling and Supportive Environments	Yes	Some what	No	Needs work
14c	If no, how can these supports be put in place?				
	Accountability				
15a	Does your organization set goals with respect to creating and improving enabling and supportive environments for people with ADRD and their families?	☐	☐	☐	☐
15b	How do you measure progress towards meeting those goals?				
15c	How else is accountability demonstrated with respect to your activities involved in creating or enhancing enabling and supportive environments (e.g., by publicly reporting on these activities, through formal and informal feedback mechanisms)?				

Our Goals for Creating Enabling and Supportive Environments

(Tip: Review the boxes checked as "Needs work")

For the Next Year

GOAL/OBJECTIVE:
(Is this a personal or an organizational goal?)

Action strategies:

Resources needed:

How we will know we've achieved the goal:
(Can this performance measure be linked to your accreditation or other processes?)

GOAL/OBJECTIVE:
(Is this a personal or an organizational goal?)

Action strategies:

Resources needed:

How we will know we've achieved the goal:
(Can this performance measure be linked to your accreditation or other processes?)

Over the Next Five Years

GOAL/OBJECTIVE:
(Is this a personal or an organizational goal?)

Action strategies:

Resources needed:

How we will know we've achieved the goal:
(Can this performance measure be linked to your accreditation or other processes?)

GOAL/OBJECTIVE:
(Is this a personal or an organizational goal?)

Action strategies:

Resources needed:

How we will know we've achieved the goal:
(Can this performance measure be linked to your accreditation or other processes?)

SECTION 3:

CREATING PERSONAL, SOCIAL AND SYSTEM CONNECTEDNESS

SECTION 3: CREATING PERSONAL, SOCIAL AND SYSTEM CONNECTEDNESS

Description

An individual, as a person, cannot be viewed in isolation. A relationship-based approach conceives of the person diagnosed with ADRD and his or her family as being actively connected with each other. Similarly, they are connected to their local community. The form and availability of health and social service resources (the "system") relevant to helping people with ADRD live meaningful lives are inextricably connected through the community to the individual. Such connectedness dictates a deliberate planning approach that recognizes and facilitates meaningful relationships at the individual, community, and service levels.

Creating personal, social and system connectedness incorporates:

- continued community participation;

- citizen input in the planning, delivery and evaluation of services/programs;

- collaboration and partnership among service providers; and

- linkages between formal and informal support sectors.

BEFORE READING ON

What "hat" are you wearing?

Before working through the checklist, decide whether you are approaching the exercise as a private individual, in your professional capacity (e.g., Public Education Coordinator), or on behalf of an organization (e.g., for a long-term care home).

A clear understanding of which "hat" you are wearing will help remove any potential ambiguity in the responses and clarify the actions forward.

Checklist Questions

Creating Personal, Social and System Connectedness	Yes	Some what	No	Needs work
Participation in the community				
1a Do you, alone or in partnership with others, allow opportunities for the continued participation of people with ADRD and their families in social and spiritual activities in the community where they live (e.g., by providing, linking with or facilitating social supports and resources such as transportation, drop-in centres, congregate dining, recreation and leisure opportunities, or access to faith leaders)?	☐	☐	☐	☐
1b How do you do this and with whom?				
1c How could you do this more?				
Full engagement in life				
2a Do you allow opportunities for people with ADRD and their families to be fully engaged in life, from early stages to later stages (e.g., nurturing their personhood, providing meaningful interactions, being inclusive, being respectful of their values, maintaining involvement in community)?	☐	☐	☐	☐
2b How do you do this?				

Creating Personal, Social and System Connectedness	Yes	Some what	No	Needs work
2c How could you do it more?				
Diversity – inclusive linkages **3a** Do you link with representatives of people with different backgrounds (e.g., language, religion, ethnicity, culture, sexuality, rural/urban residence) in developing appropriate services and programs for all people with ADRD and their families?	☐	☐	☐	☐
3b If yes, how do you do this?				
3c If no, what is needed to enable you to do this?				
A strong, relationship-based care team **4a** Does your organization facilitate, value and respect the relationships among a broad range of stakeholders, including people with ADRD, their families and other partners in care, staff at all levels, and volunteers, i.e., foster a strong care team?	☐	☐	☐	☐

Creating Personal, Social and System Connectedness	Yes	Some what	No	Needs work
4b How do you do this? How could you do it more?				

Opportunities for input

5a Do you and your organization provide meaningful opportunities for all those involved in the dementia care continuum, including people with ADRD and their families, to contribute their perspectives and expertise in decision-making, planning, delivery and evaluation of practice?

	Yes	Some what	No	Needs work
• People with ADRD?	☐	☐	☐	☐
• Families and other partners in care?	☐	☐	☐	☐
• Staff at all levels?	☐	☐	☐	☐
• Volunteers?	☐	☐	☐	☐

5b If yes, how do you do this?

5c If no, do you play a role with others who provide these opportunities? What is needed to facilitate this process?

Community-wide partnerships

6a Have you established strong partnerships, built on mutual respect and support, with others in the community as you work to improve the quality of life of people with ADRD and their families in your community? For example:

	Yes	Some what	No	Needs work
• Do you and your organization devote time in day-to-day practice to building strong relationships with others?	☐	☐	☐	☐

Creating Personal, Social and System Connectedness	*Yes*	*Some what*	*No*	*Needs work*
• Do you and your organization partner and collaborate with others in the community (including sectors such as housing, transportation, recreation and leisure services) to identify and minimize service gaps in your community by planning, implementing and evaluating joint services/programs?	☐	☐	☐	☐
• Do you and your organization partner and collaborate with others to advocate to government and the Local Health Integration Networks (LHINs) for any policy and funding changes that may be needed?	☐	☐	☐	☐
6b How could you do this more?				

Sharing knowledge/building capacity				
7a Does your organization have formal mechanisms for sharing knowledge in the ADRD community of interest, thus expanding and enhancing the ability to care for and support someone with ADRD?	☐	☐	☐	☐
7b What are those formal mechanisms?				
7c How do you personally share knowledge with others in the ADRD community? How could you do more?				

Creating Personal, Social and System Connectedness		*Yes*	*Some what*	*No*	*Needs work*
8a	**Accountability** Does your organization set goals with respect to creating and improving the connections between the individual, family, community and service providers (e.g., collaborations, partnerships)?	☐	☐	☐	☐
8b	How do you measure progress towards those goals?				
8c	How else is accountability demonstrated with respect to your activities towards creating and improving the connections between the individual, family, community and service providers (e.g., by publicly reporting on these activities, through formal and informal feedback mechanisms)?				

Our Goals for Improving Personal, Social and System Connectedness
(Tip: Review the boxes checked as "Needs work")

For the Next Year

GOAL/OBJECTIVE:
(Is this a personal or an organizational goal?)

Action strategies:

Resources needed:

How we will know we've achieved the goal:
(Can this performance measure be linked to your accreditation or other processes?)

GOAL/OBJECTIVE:
(Is this a personal or an organizational goal?)

Action strategies:

Resources needed:

How we will know we've achieved the goal:
(Can this performance measure be linked to your accreditation or other processes?)

Over the Next Five Years

GOAL/OBJECTIVE:
(Is this a personal or an organizational goal?)

Action strategies:

Resources needed:

How we will know we've achieved the goal:
(Can this performance measure be linked to your accreditation or other processes?)

GOAL/OBJECTIVE:
(Is this a personal or an organizational goal?)

Action strategies:

Resources needed:

How we will know we've achieved the goal:
(Can this performance measure be linked to your accreditation or other processes?)

LINKS AND RESOURCES

A. Links

Accessibility Directorate of Ontario, Ministry of Community and Social Services:
http://www.mcss.gov.on.ca/mcss/english/pillars/accessibilityOntario

Advocacy Centre for the Elderly - Information on legal capacity, health care consent, powers of attorney, rights of residents in long-term care, etc.:
www.advocacycentreelderly.org

Alzheimer Knowledge Exchange – an online resource linking people, resources and ideas: www.akeontario.org

Alzheimer Society of Ontario and local chapters: www.alzheimeront.org

Canada Council on Health Services Accreditation: www.cchsa.ca

Community Care Access Centres - CCAC locator:
http://www.oaccac.on.ca/ccac_locator/index.php

Community Legal Education Ontario - free pamphlets and booklets on legal rights:
www.cleo.on.ca

Dementia Care Institute – The proposed Dementia Care Institute, supported by the Alzheimer Knowledge Exchange, will bring together the dementia care community to promote and facilitate the application of best dementia care and support practices using the knowledge exchange and transfer cycle. A recommendation of the Health Human Resources Strategy (see below) and available on the Alzheimer Knowledge Exchange.

Dementia Networks:
http://alzheimerontario.org/English/dementia%20networks/default.asp?s=1

First Link - linking those newly diagnosed with ADRD and their families with local supports and resources: http://alzheimerott.org/first_link/index.htm

Health Care Consent Act – see "Laws" on Government of Ontario website at
www.gov.on.ca

Health Human Resources Strategy – provides recommendations for an ADRD health human resources strategy on issues that include: the impact of ADRD as a co-morbid condition, education, training and upgrading, building integrated dementia care (Dementia Care Institute), recruitment, quality of work life and employee retention, future role and support for PRC and PEC positions, and "in the field" leadership support. An appendix identifies recommended core competencies in dementia care. Available on the Alzheimer Knowledge Exchange, www.akeontario.org.

Local Health Integration Networks (LHINs) including links to each of the 14 LHINs:
http://www.lhins.on.ca

Ministry of Health and Long-Term Care: http://www.health.gov.on.ca/

_____, Seniors' Care:
http://www.health.gov.on.ca/english/public/program/ltc/ltc_mn.html

Murray Alzheimer Research and Education Program (MAREP): MAREP integrates research and educational activities in dementia care. http://marep.uwaterloo.ca/

National Advisory Council on Aging (NACA): http://www.naca.ca/

Ontario Community Support Association: http://www.ocsa.on.ca/

Ontario Safety Association for Community and Healthcare - a non-profit corporation and a "designated entity" under the *Workplace Safety & Insurance Act* with the overall goal of reducing the rate of lost time injuries: http://www.osach.ca/

Ontario Seniors' Secretariat, Ministry of Citizenship and Immigration:
http://www.citizenship.gov.on.ca/seniors/index.html

***Personal Health Information Protection Act* (PHIPA) -** – see "Laws" on Government of Ontario website at www.gov.on.ca

SeniorsInfo.ca: A website that provides information about seniors' programs and services available from all levels of government and local community agencies in 22 communities across Ontario. http://www.seniorsinfo.ca/

Seniors Health Research Transfer Network (SHRTN): Links caregivers, researchers and policy makers involved in community and long-term care for seniors - http://www.shrtn.on.ca

Substitute Decisions Act – see "Laws" on Government of Ontario website at www.gov.on.ca.

B. Resources

ADRD Planning Framework, produced by Ontario's Roundtable for Future Planning for those Affected by ADRD, (2006) and available through the Alzheimer Knowledge Exchange.

Alzheimer Knowledge Exchange – an online resource linking people, resources and ideas: www.akeontario.org

Core competencies in dementia care – see Health Human Resources Strategy on the Alzheimer Knowledge Exchange.

Enhancing Care through the Guidelines for Care, produced by the Alzheimer Society of Canada and Alzheimer Society of Ottawa (2004). Provides strategies for how to implement the ASC's Guidelines for Care in long-term care facilities and day programs. Each guideline is presented with goals and objectives to assist organizations in identifying areas of success and future needs, assessment criteria and resources and support material.

First Link - linking those newly diagnosed with ADRD and their families with local supports and resources: http://alzheimerott.org/first_link/index.htm

P.I.E.C.E.S. - Training based on a framework of assessment and supportive care strategies for those working in long-term care homes, CCACs and contracted agencies of CCACs: http://www.piecescanada.com/.

Psychogeriatric Resource Consultants (PRC) - Contact information available through the Alzheimer Knowledge Exchange/AKE Community Groups.

Public Education Coordinators (PECs) - PECs raise awareness and provide education, support services and volunteer training. To contact the PEC in your area, please call your local chapter of the Alzheimer Society of Ontario: http://www.alzheimeront.org.

Seniors Health Research Transfer Network (SHRTN) - Links caregivers, researchers and policy makers involved in community and long-term care for seniors - http://www.shrtn.on.ca

U-First! - An education program for supervisors and frontline workers that provides a common knowledge base, common language, common values and a common approach to providing care for persons with ADRD: http://www.u-first.ca/

C. Local Resources

Your Alzheimer Society chapter(s):

Your Dementia Network:

Your Local Health Integration Networks (LHINs):

Your Community Care Access Centre

Your Psychogeriatric Resource Consultant(s):

Your Public Education Coordinator(s):

Other local resources:

APPENDICES

Appendix A: Roundtable Membership and Other Participants

Appendix B: ADRD Planning Framework Diagram

Appendix A: Roundtable Membership and Other Participants

**The Roundtable on Future Planning
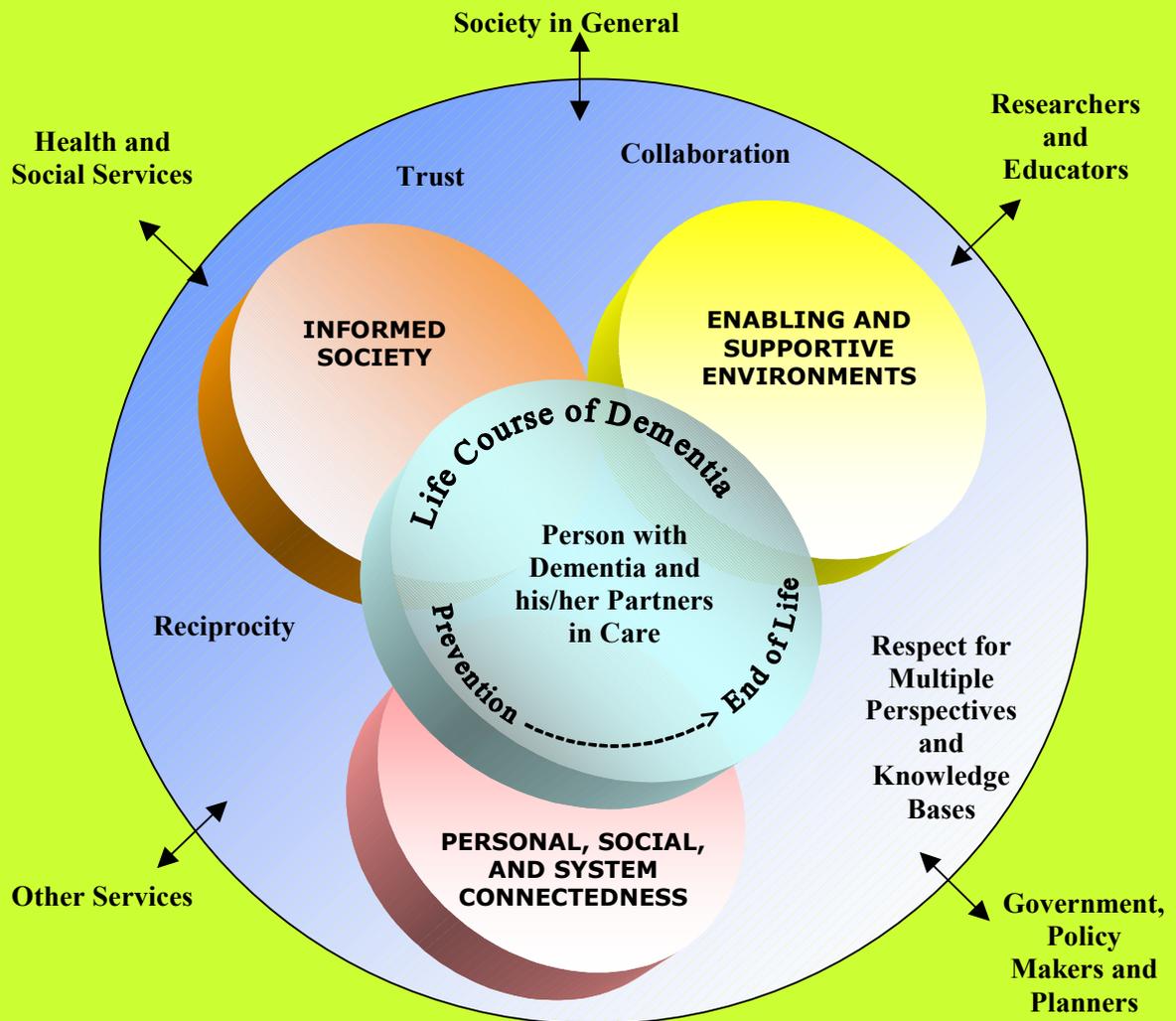for People Affected by Alzheimer Disease and Related Dementias**

Co-Chairs	
The Honourable Mario Sergio, MPP (to March 2006) **The Honourable Bob Delaney, MPP** (after March 2006) Parliamentary Assistant to the Minister Responsible for Seniors **Mr. Geoff Quirt** Assistant Deputy Minister – Ontario Seniors' Secretariat, Ministry of Citizenship and Immigration	
Members	
Dr. Brian Aitken (Laurentian University) * Det. Pat Blake (Hamilton Police) Mr. Alan Cimprich (Citizen) * Dr. Sherry Dupuis (MAREP, U. of Waterloo) * ~ Dr. John Feightner (University of Western Ont.) Dr. Luis Fornazzari (CAMH) Ms. Amy Go (Yee Hong Center for Geri. Care) * Dr. Michael Gordon (Baycrest Centre for Geri. Care) Mr. Al Gorlich (Citizen) Ms. Diane Harris (P.I.E.C.E.S. Canada) Dr. Ken Le Clair (PCCC – Kingston) * Dr. Parminder Raina (McMaster University)	Ms. Frances Maone (VAC) Ms. Lori Moran (University of Alberta) Ms. Judy Muzzi (United Senior Citizens of Ont.) * Ms. Sandra Pitters (City of Toronto) Dr. Dorothy Pringle (University of Toronto) Ms. Vania Sakelaris (MASA) (Nov. '04 – Oct. '05) Ms. Barbara Schulman (DN – Champlain)~ Ms. Linda Stebbins (ASO) Ms. Anne Stephens (St Michael's Hospital) * Ms. Mary Sylver (Ont. Prevention Clearinghouse) Ms. Marilyn Truscott (Citizen) Ms. Judith Wahl (ACE) * ~

Ex-Officio Members	ASTP Staff
Mr. Michael Klejman (MOHLTC) Ms. Cheryl Szikita (MOHLTC) Ms. Elizabeth Esteves (MCI-OSS) Ms. Angie Szuch (MCI-OSS) Ms. Mercedes Zonan (PA's Office to March 2006) Mr. Andrew Matheson (PA's Office after March 2006)	Mr. Eric Hong, Project Manager (to March 2006) Mr. Scott Macpherson, Project Manager (from April 2006) Ms. Anne Anderson, Research Analyst Ms. Katherine MacDonald, AKE Coordinator Ms. Joan Honsberger, Project Officer Ms. Karen Parrage, Administrative Assistant

Guest Participants	
Ms. Marg Eisner (Alzheimer Society of Ottawa) Ms. Karen Henderson (Caregivers' Ass. of Ont.) Ms. Salinda Horgan (PCCC – Kingston) * ~ Ms. Frances Morton (MAREP, U of Waterloo) ~	Dr. Mark Oremus (McMaster University) Ms. Cecile Raymond (Toronto – CCAC) Ms. Susan Thorning (OCSA)

*   Member of the Framework Working Group
~   Member of the Toolkit Working Group

Appendix B: ADRD Planning Framework Diagram

Vision

Ontario as a society where all persons with ADRD and their partners in care live meaningful lives across the progression of the illness through active personal and community engagement.

Guiding Principles

- **A Relationship-Based Approach**
- **Ethical Principle of "Do No Harm"**
- **Citizenry Rights**

- **Respect for Diversity and Inclusiveness**
- **Fairness in Eligibility and Accessibility**
- **Accountability**

Society in General

Researchers and Educators

Health and Social Services

Trust

Collaboration

INFORMED SOCIETY

ENABLING AND SUPPORTIVE ENVIRONMENTS

Life Course of Dementia

Person with Dementia and his/her Partners in Care

Prevention --------------> End of Life

Reciprocity

Respect for Multiple Perspectives and Knowledge Bases

PERSONAL, SOCIAL, AND SYSTEM CONNECTEDNESS

Other Services

Government, Policy Makers and Planners

Enabling Mechanisms

- **Government Policy, Support and Adequate Resource Allocation**
- **Legislated Processes and Legal Mandate**
- **Engagement of ADRD and Broader Communities in Planning**

- **Community-Based Partnerships Enabling Collective Wisdom**
- **Performance-Based Service Planning, Delivery, and Evaluation**

Outcome

Ontario as a society where all persons with ADRD and their partners in care live meaningful lives across the progression of the illness through active personal and community engagement